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For Eric and Vicki Merrill, the diagnosis was terrifying.

The couple's son, Sean, who was then 8 years old, had always seemed perfectly healthy. But doctors were now telling the family Sean was not well, and about to get far sicker.

Their happy and apparently healthy boy suffered from a rare genetic disorder, Mucopolysaccharidosis (MPS). The disease, which is caused by an enzyme deficiency and is typically fatal, afflicts only a few dozen births each year in the United States.

The disease causes a range of physical and mental disabilities, including organ failure, stunted growth and brain damage.

After the diagnosis the Merrills had their younger son, Cody, tested.

They received more bad news. Cody had MPS as well.

Even worse than the diagnosis was the prognosis. Because the disease is so rare, no treatments were available.

Parents had few options, other than to make their children as comfortable as possible before the inevitable.

That changed shortly after Sean's diagnosis, a little less than a decade ago, after researchers discovered a treatment that arrests most of the physical manifestations of MPS.

For the Merrills, it was a burst of hope.

"It was a straw to grasp, something to hold on to," said Eric Merrill.

The family was able to enroll one child, Sean, in a clinical trial in New York in 2001.

For nine months, the Merrills flew from St. Louis to New York every week so Sean could receive the experimental treatment.

The treatment proved effective.

Soon both sons were on the medication, greatly enhancing their prospects for a longer and more fulfilling life.

One hurdle remained, however - cost.

One month's worth of treatment for the two boys costs a jaw-dropping \$800,000.

"We have a home health nurse and they have a four-hour IV infusion once a week," Eric Merrill said. "The drugs are biologics, which are medicines made from living organisms. Because of this there will never be a cheaper, generic form."

Fortunately for the Merrills, Eric's private health insurance has paid for treatment, the total cost of which has risen into the multi-millions.

Not every family is so fortunate.

Even those with insurance often have lifetime caps in the range of \$1 million - not even enough to pay for two months treatment for the Merrill family.

While the family's insurance is covering costs now, the children will not remain covered forever. Once Sean, who is almost 17, and Cody are adults and no longer eligible for coverage, they will face medical bills in the neighborhood of \$10 million annually, leaving government assistance as the only option. Both will qualify for Medicaid, but only as long as they do not work full-time.

Currently, individuals earning more than \$600 each month are ineligible for Medicaid.

That places the Merrills in a tough situation.

To keep their medical coverage, both Cody and Sean cannot work.

That doesn't sit well with the Merrills.

"We want them to be able to work," Eric Merrill said. "We don't want them to have to sit on the couch all day. They want to be productive members of society. They have dreams and the Medicaid system is telling them they can't."

To remedy this, the Merrills and other MPS families have been lobbying government officials to pass the Ryan Dant Act.

The bill's namesake is a Texas man with MPS whose family was instrumental in raising the necessary funding to develop MPS treatment.

The Dant family invited the Merrills to visit Washington, D.C., to lobby legislators on behalf of the bill.

The Merrills visited U.S. Rep. Russ Carnahan, D-St. Louis, and convinced him to co-sponsor

the legislation.

"He was very gracious and we convinced him to be the lead Democrat on the bill," Eric Merrill said.

Carnahan became aware of the legislation after the Merrills wrote a letter to his office asking for support.

"This bipartisan piece of legislation makes a lot of sense and I am hopeful that given the added support it has a real chance of becoming law so that people like Sean and Cody are not limited by disease," Carnahan said.

The legislation now has more than 30 co-sponsors.

If the Ryan Dant Act passes in its current form, anyone whose medication costs more than \$200,000 annually would be allowed to work and receive Medicaid benefits.

While that would include the fewer than 1,000 individuals with MPS in the United States, it would also cover thousands of others who suffer from diseases whose treatments are prohibitively expensive, such as hemophiliacs.

Vicki Merrill is hopeful the legislation will pass.

"We're thrilled by the possibility they could enter the work force and be treated like anyone else," she said. "We want them to live a normal life and be insured."

They also want to assist others.

"Sean is almost 17 and he's said he wants to help his brother and all of the other kids after them," Vicki Merrill said. "That's important to him, and to us."

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